Utah Registry of Autism and Developmental Disabilities

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Welcome!

The Utah Department of Health welcomes all to the second edition of the Utah Registry of Autism and Developmental Disabilities' newsletter! We want this quarterly newsletter to be useful for you and your family. Please send your comments or suggestions to us by phone at (801) 584-8547or via email to jeniferlloyd@utah.gov

Behavior Skills

Each edition of this newsletter will include a behavior skills section – it will talk about a behavior topic that many families have had to address. While this section cannot and does not take the place of a visit with a clinician or other behavioral specialist, we hope that you will find the suggestions useful. For this newsletter, we have some useful tips on addressing behavior problems from Judith Miller, Ph.D. Dr. Miller is a child psychologist who works with the University of Utah Medical Center Department of Psychiatry.

Consider the Source: Autism Spectrum Disorders and Behavior Problems

Like other children, children who have an Autism Spectrum Disorder (ASD; including Autism, Asperger Disorder, and PDD-NOS) may also have behavior problems such as being aggressive, or saying or doing inappropriate things. For these children, their behavior problems may be best understood (and dealt with) by understanding the core biological problems associated with their ASD. For example, some children who have an ASD show aggression on the playground because they do not understand how to join in a group. Others become very upset for no apparent reason or over something that seems minor; this may be because they are over-stimulated by things that most people do not even notice.

Here are two examples of children with serious behavior problems that were not responding to the usual methods used to correct behavior but responded well when the intervention considered the biological problems associated with their ASD. These are two true accounts, with the names and details changed to protect their privacy.

Andrew: Andrew was a bright young man with an ASD in a regular education elementary school classroom. His teacher was concerned about his unpredictable behavior; sometimes he was calm and able to do his schoolwork, other times he became extremely frustrated and his behavior quickly got worse to the point that he would push desks across the room, throw chairs, etc. The use of traditional penalties was not working. One approach might have been to provide a reinforcer for each few minutes that Andrew remained calm, but this would have taken a lot of time, and would not have addressed the real reason why Andrew's aggression came out so unpredictably. However, because we knew that Andrew

had an ASD, we had some ideas about why the behavior was occurring. The behavior seemed to occur most often when there was a change in the daily routine. Difficulty with changes in routine is a classic characteristic of an ASD; it is part of the diagnosis and it is biological in nature. Changes in routine are overwhelming to people who have an ASD. However, people with an ASD can better deal with such changes when they have a visual schedule that tells them what is going to happen and when.

Solution: This child's teacher began taping a small daily schedule to the corner of Andrew's desk each morning. She found that it immediately got rid of the aggressive episodes. The few moments she spent each morning to type and print out the schedule took much less of her day than the time she would have needed to address a meltdown (and its subsequent aftermath). One day there was a last-minute change and she didn't have time to print out another schedule. She walked over to Andrew's desk, and calmly explained that she needed to change his schedule. While he watched, she crossed out one activity and wrote in the new activity. Andrew looked at the schedule, said, "Okay" and went back to work. The teacher was amazed; this is the kind of event that weeks before would have resulted in a major meltdown.

By using a visual schedule the teacher helped Andrew learn an important skill: how to understand schedule changes. Once he understood them, his frustration and aggressive behavior faded. It also took less time and man-power to make daily visual schedules than it would have required to provide Andrew with a constant reinforcement for "keeping his body calm." More importantly, by teaching Andrew this skill, he will be able to create and manage his own schedules as he continues to grow.

Matthew: Matthew was a bright young man in high school who had an ASD. He did not have any friends, and usually did things by himself. However, he was keenly interested in the opposite sex. He frequently talked about his desire to have a girlfriend, but did not understand how to go about getting one. His understanding of relationships was based on what he had seen in movies and on television, and in watching people kiss or hug in public. This was what he wanted. When people tried to explain the time and effort involved in developing a relationship he would become extremely upset. That is not how it seemed to occur in movies (after all, they can go from complete strangers to getting married in an hour or two), and did not seem to fit with what he saw his peers doing (remember, he did not have friends, he simply saw his peers during school hours).

Matthew began approaching girls and asking them to be his girlfriend. Sometimes, he would ask them to do things he saw in movies. Adults tried to explain to him that this was wrong, but that did not make sense to Matthew. Eventually he received several "sexual harassment" complaints at school. While he nodded in agreement when people tried to explain what was wrong with his behavior, he seemed unable to remember this the next day. Soon he was not allowed to leave the house on weekends or evenings because his family was petrified that he would approach another girl in public and get beaten up or arrested.

At this point, Matthew was provided a list of appropriate things to say to girls. With the threat of a major punishment, he was able to use the list for a day or so. However, it did not affect the underlying problem of Matthew still not understanding why his behavior was taken so seriously and negatively. After all, his intent was friendly and positive.

Solution: A visual approach was taken to explain relationships to Matthew. Several columns were drawn, with different levels of relationships in each. The first column was labeled "Strangers you might get to know" and included a definition and examples (people at a party, guests at a wedding, children in your math class, people at the lunch table, etc.). Then a list of appropriate activities and conversations topics was included for this group. The next column was titled "Acquaintances" and again included a definition, examples, and a list of appropriate activities and conversation topics. This continued through more relationships: general friends, close friends, best friend, general dating, a girlfriend, and finally a committed relationship (e.g.,

marriage). When appropriate, columns also listed the amount of time required to set up this level of a relationship (e.g., "to be considered a girlfriend, you would have had to date that person exclusively, see them several times a week and be together for dating activities about once a week or so, for at least 3 months, and the two of you would have had to tell each other that you are boyfriend and girlfriend").

Matthew understood the columns, and took the information in them word for word. When we talked about relationships, we tied our discussion back to the spreadsheet to help clarify and enhance his understanding. During one of our discussions, Matthew suddenly understood why people took his inappropriate behavior so seriously. The activities he was suggesting (being a girlfriend, kissing) were not in the same column as the type of person he was asking (strangers or acquaintances). Seeing how many columns were in between also helped him realize why his behavior was so serious. He was able to understand that people in the first couple of columns (strangers and acquaintances) would feel frightened if he asked them to do something that occurred in the other columns (dating or committed relationships), and they might think Matthew was trying to scare them or hurt them.

Now Matthew understood why his behavior was wrong, and it was much easier for him to stay out of trouble. He still wanted a girlfriend, but now he had the information he needed to know about what is involved in developing a relationship and he was not as frustrated and impatient. He also saw the value of developing friendships in general. The use of a visual format to provide clear information about how relationships work dealt with Matthew's ASD problems, especially his limited ability to understand social situations and his trouble managing non-visual information. Instead of chasing the symptoms (his improper social gestures) we addressed the cause and gave him information and skills that will help him participate in society.

There are many other times when it works best to address a behavior problem by understanding problems associated with the ASD. For example, the child who hits classmates in frustration and cannot understand why they don't want to play with him the next day might need a visual way to learn that people remember what happened yesterday and think it might happen again today. The child who pokes people in line because she's over-stimulated by the change to a new activity might need information about what's happening next and have a list of some proper things to do while waiting. The child who is rejected by peers because he picks his nose might need some clear rules about hygiene because it is unlikely that he will pick up on the social cues that this behavior is unacceptable. The child who has problems in the afternoon because the unstructured lunch recess is very stressful to her might need a few minutes of "down time" either right before or right after lunch so she can have a break and refresh for the rest of the afternoon.

So, when you want to address a problem behavior in a child with an ASD, first consider how their disorder is shaping their behavior. Addressing this issue is often the fastest and most effective way to change a problem behavior. It is also an opportunity to teach important skills the child will need for the rest of his or her life.

Families' Corner

In this section of the newsletter someone whose life has been impacted by an autism spectrum disorder or other developmental disability offers his or her perspective. If you are interested in writing an article for a future newsletter, please contact us.

Our parent contributor for this newsletter is Jenifer Lloyd. Jenifer is an epidemiologist for the URADD project, and a co-editor for this newsletter. She resides in Salt Lake City with her husband, Mike, and their nine-year-old daughter, Maura.

Our daughter, Maura, was born with profound disabilities (she had a massive stroke shortly after she was born). We soon faced several dire predictions. First, she was not supposed to live. If she made it past a few months, she was predicted to survive two to three years in essentially a

vegetative state. Fortunately, neither scenario occurred. Maura grew and slowly met some (not all) of those developmental milestones that professionals (and parents of children with disabilities!) know by heart. Maura's basic medical needs were similar to those of other children. We just had some extras – therapy, special shoes, glasses, etc. However, some of Maura's behavior was unusual, and the 'typical' discipline suggestions on how to improve it didn't fit.

Despite the differences between Maura and the children described in Dr. Miller's article, Maura also responded to a biological technique to correct a 'behavior problem'. When Maura started preschool, her teacher reported that she kept falling asleep in class. Our first response was to put her to bed earlier – Maura wasn't happy about this and let us know it. We worked with her teacher to try different techniques to keep her awake. The sleeping just didn't make sense! Maura seemed to enjoy preschool – why would she want to miss a minute of it? Then we thought about *why* Maura would be falling asleep. After speaking to professionals who work with brain injuries, we came to understand that Maura would likely never have the stamina to stay awake through a whole school day. Her naps weren't the result of not enough sleep and they weren't a behavior problem. They were a normal biological response to a massive brain injury. Problem solved and it only took us three months to figure it out! Maura has now regulated herself to a 10-20 minute catnap at school usually right after lunch. We make sure her teachers and everyone who works with her understand that these are 'non-negotiable' naps.

I'm often amazed at Maura's patience, with her parents and with all those who work with her. When we use a '<u>Why</u> is she doing that?' approach to a address a behavior problem we get so much further (so much faster) than when we use the knee-jerk 'Just stop it' approach. That knowledge, however, hasn't kept us from occasionally returning to the 'Just stop it' approach. Fortunately for us, Maura is amazingly patient.

What's New?

This section of the newsletter will include a summary of a recent research article that looks at autism spectrum disorders or other developmental disabilities. If you are interested in reading the entire article, you can get it from your library, or contact us and we will help you get a copy.

Article Name: Methylphenidate for pervasive developmental disorders: safety and efficacy of acute single dose test and ongoing therapy: an open-pilot study.
Authors: DiMartino A, Melis G, Cianchetti, Zuddas A.
Summer 2004
Journal reference: *J Child Adolesc Psychopharmacol 2004 Summer; 14* (2): 207-218.

This study evaluated the use of methylphenidate (Brand name: Ritalin©) in 13 children with autism spectrum disorders who were also diagnosed with hyperactivity. The study looked at if and how this drug would change the children's behavior and whether it was safe to use.

The researchers used psychological tests to measure the children's level of hyperactivity and their autistic behaviors before and after giving the children a dose of methylphenidate (MPH). They found that within an hour after receiving a single dose of MPH, five of the 13 children had increased hyperactivity and more autistic behaviors. These children were not given any additional doses of MPH. Four of the other children in the study had decreased hyperactivity, and the remaining four had no change in behavior. The eight children in these two groups continued to receive a daily dose of MPH. After the first week of the study, two of the eight children showed no change in their hyperactivity; these children were given no further doses of MPH. The remaining six children received a daily dose of MPH for a 12-week study. Psychological tests were done on the remaining six children at 4- and 12-weeks.

At the end of the 12-week study, the researchers found that these six children continued to have decreased hyperactivity but no change in their autistic behaviors. The researchers also asked parents about any adverse effects from MPH in all the children who participated in the study; no adverse effects were noted.

The researchers concluded that a single dose of MPH given to children who have both an ASD and hyperactivity might safely and quickly identify those children who would not benefit from taking this drug, as well as those who might benefit.

Upcoming Events

This section of the newsletter includes a list of upcoming events that we think you might find of interest. If you know of an upcoming event that parents and families affected by autism spectrum disorders or other developmental disabilities would appreciate, please call 801-584-8547 and let us know. Also, check our website under 'Research and Training' to get more details about these upcoming events: www.health.utah.gov/autism/Research.htm

November 3-4, 2004: Annual Parent Training Conference 2004 at the Carmen B. Pingree School for Children with Autism – call 801-581-0194

November 4-5, 2004: Critical Issues Facing Children and Adolescents at the Hilton Salt Lake City Center – call 801-501-9446

November 11-13, 2004: Annual Autism Conference at the Larry H. Miller Campus of Salt Lake Community College – call 801-272-1051 or 1-800-468-1160

A Reminder and a Request for Help!

Please visit our website and tell others about it: www.health.utah.gov/autism We update it monthly. If you would like something on the website that you don't see there, please contact us and let us know.

Finally, URADD needs your help! We want all Utah families affected by an autism spectrum disorder or other developmental disability to know about us. If you know other families who fit this description, please share this newsletter with them, or tell them about our website.

Become Part of the Utah Registry of Autism and Developmental Disabilities!

The Utah Registry of Autism and Developmental Disabilities is always looking for Utah residents who have an autism spectrum disorder to become part of the registry. The registration form is available online: www.health.utah.gov/autism/Registry.htm You can also request a registration form over the phone, by fax, or by mail (Please see the contact information in the next column.).

To contact us:

Mailing Address

Utah Registry of Autism and Developmental Disabilities
Utah Department of Health
P.O. Box 144643
44 North Medical Drive
Salt Lake City, UT 84114-4643
URADD@utah.gov

Phone Numbers

Within Salt Lake City: (801) 584-8547
Outside Salt Lake City: (800) 829-8200 Ext. 1
Fax: (801) 584-8579

URADD Investigators

Dr. Judy Pinborough Zimmerman
Children with Special Health Care Needs
Utah Department of Health
44 N. Medical Drive
Salt Lake City, Utah 84114

Dr. William McMahon
University of Utah School of Medicine
Department of Psychiatry
50 N. Medical Drive
Salt Lake City, Utah 84132